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Treatment choice in Adolescents with Cleft Lip and/or Palate: the importance of Shared Decision-Making

Wogden, F

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Design: Parents and professionals completed mixed-methods questionnaires about the degree to which children had been involved in choices about elective treatments. Data were analysed using content analysis. Young people aged 12 to 25 years were asked to take part in semi-structured interviews. The data were analysed using inductive thematic analysis.
Setting: Questionnaire data collection took place online, and interview data were collected via messenger or telephone-based interviews.
Participants: The study employed 30 participants; 11 young people (3 male, 8 female), 17 parents (13 Mothers, 4 Fathers) and 5 professionals (two surgeons, two speech and language therapists and one paediatric dentist).
Results: Five main themes were identified. These reflected participants feeling that with increasing age should come increased involvement in decision-making and that it was important for adolescents to "have a voice" during decision-making. Parents, peers and health professionals were identified as influencing decisions. Most adolescents reported overall satisfaction with their involvement in decision-making, but sometimes felt 'left in the dark' by professionals or under pressure from parents. A desire to improve speech and/or appearance was as an area where adolescents wanted to be more involved in decision-making.
Conclusions: Shared Decision-making is an important factor for psychological well-being by promoting autonomy and self-esteem amongst adolescents with CL/P.

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Introduction

Cleft lip and/or palate (CL/P) are the most common birth defects in babies (Setó-Salvia and Stanier, 2014). Required treatments for CL/P begins early in life and continue throughout childhood and adolescence. While some elective lip and nasal revisions can occur around the age of 4-6 years, many more elective treatments for CL/P are available at approximately aged 12 onwards and include rhinoplasty (Vass et al., 2016), orthognathic surgery (Daskalogiannakis and Mehta, 2009), secondary speech surgery, further speech and language therapy and revisional lip surgery (Chuo et al., 2008).

Traditionally, medical decision-making dynamics involved healthcare professionals (HCPs) dominating the decision-making process (Barry and Edgman-Levitan, 2012), with them. More recently, medical decision-making has moved towards a person-centred approach, in which service users actively engage in decisions surrounding their healthcare; a process known as shared decision-making (SDM; Ting et al., 2014). There is growing awareness that service users are the best experts regarding their preferences and goals for treatment (Ting et al., 2014). SDM decreases decision conflict for elective treatments, increases confidence in decisions, and promotes health and well-being (Boss et al., 2016).

SDM with children and adolescents, is complex due to concerns surrounding children's ability to fully understand the implications of treatment decisions, the child's position in the three-way relationship between parents and HCPs and the protective nature of parents and HCPs (Coyne and Harder, 2011). The ability to engage in effective decision-making is associated with changes in cognitive maturation that take place through the period of adolescence. Specifically, changes in regions of the frontal allows for greater cognitive functioning, particularly in relation

to executive skills (e.g. planning, impulsivity and decision-making). These frontal lobe changes start at around 10-12 years of age and then develop over the adolescence until around the age of 22 years (Gogtay et al, 2004). This allows for more reasoned decisions to be made through better weighing up of important information, increased logic abilities and advances in moral development (Gogtay et al, 2004; Kohlberg, 1958).

As these changes take place over time, the decision-making capacity of a 12 year will be significantly different to that of a 17 year old. Hospital policies recognise these changes and the importance of child-centred care and acknowledge children have the right to make informed decisions before the official age of informed consent of 16 years (Coyne, 2008; Department of Health, 2009). This usually includes the use of the process of assent, where parents give consent for treatment but adolescents confirm their willingness and preferences for treatments (Kuther, 2003). Coyne et al., (2014) found that children's involvement in SDM was limited prior to 16 years but they appeared comfortable with adults taking responsibility for major treatment decisions as long as they received appropriate information, had choice in how their treatments were managed and could voice preferences.

Alongside the cognitive changes, adolescents should be allowed the opportunity to start to take control and responsibility for their own decisions to enable positive adjustment and autonomy (Van Petegem, et al, 2012). Parents should gradually move from a position of decision-making authority to providing emotional support and guidance in decision-making, part of the process of SDM with involvement being decision-specific and age-related (Keller & Whiston, 2008). Low self-esteem and poor self-confidence are associated with parents who strictly control decision-making

during this time (Koerner & Fitzpatrick, 2004). Having a child born with CL/P can initially result in feelings of shock, guilt and grief (Kapp-Simon, 2006) and parents must learn to adjust to the changes in family dynamics to meet the child's needs, cope with their own feelings and manage ongoing medical procedures. In some cases, this can result in an overprotective parenting style which may discourage autonomy (Beacham and Deatrick, 2013; Pinquart, 2013). Consequently, this may cause a child to feel reluctant in challenging their parents and HCPs regarding cleft treatment decisions. Additionally, parents may need encouragement to believe in their child's capabilities surrounding SDM with many parents rating their child's functional autonomy as lower than their children (Butner et al., 2009).

Some adolescents with CL/P have appearance and speech difficulties, leading to them feel different from their peers, experiencing and can significantly impact social experiences and emotional well-being (Hunt et al, 2006; Rumsey and Stock, 2013). This makes it crucial for adolescents to be able to voice their concerns, have a sense of control over their treatment and receive support to promote well-being and positive self-concept.

Previous research has already explored parents and HCPs' perspectives surrounding SDM (see Jackson et al., 2008; Vaknin and Zisk-Rony, 2010; Lipstein et al., 2012). Nelson et al., (2012) assessed parents' experiences of decision-making for children with CL/P opting to have elective treatments focused on appearance, speech, or function. Although parents generally felt included in important decisions about their child's treatment, they relied heavily on the leadership of HCPs during the process. Nelson et al. found parents were concerned with 'doing the right thing' for

their children in relation to cleft treatments and felt elective treatments aided social functioning and enabled adolescents to meet their full potential.

Very few studies have gone further and examined SDM from the perspectives of adolescence (Hein et al., 2015). There is a need for the representation of the adolescent voice in research surrounding SDM to inform future clinical practice and research (Schalkers et al., 2016), where these have previously been extensively underrepresented (Hall et al., 2013) with no research to date surrounding adolescents with CL/P and SDM.

The current study aims to address the gap in the literature by exploring the perspectives and experiences of adolescents with CL/P in SDM by addressing central questions about whether they want to be more involved in medical decision-making, feel they are being involved in decisions about their treatment, and what kinds of decisions they would like more involvement in. Finally, the study will explore the importance of SDM for the psychological well-being of adolescents with CL/P.

Method

Participants

The study employed 30 participants across three stages of recruitment. The first and second stages consisted of five HCPs (two surgeons, two speech and language therapists and one dentist) and 17 parents (13 Mothers and 4 Fathers) who were asked to complete online questionnaires about their involvement in choices about elective treatments associated with CL/P. The final stage recruited 11 young people with CL/P (eight female and three male), aged between 12-25 years, in semi-structured interviews about involvement in decisions about elective CL/P

treatments. Interviews took place either over the phone or through an online messenger system, a preference expressed by the participants and which mimics a more realistic real-world interaction to that experienced with their own social network, helping to build rapport and reduce distress associated with appearance concerns (Fox et al, 2007). All participants were from the UK, but two of the children were temporarily living elsewhere (New Zealand and US).

An age range of 12-25 years for young people with CL/P was selected due to the natural progression of increased involvement in SDM at approximately 10-12 years old (Tates et al., 2002), and those over the age of 18 years were included to enable them to reflect retrospectively on their experiences of elective treatments. Additionally, the availability of elective cleft treatments increases from the age of 12 years onwards (Gaggl et al., 1999). The limit of 25 years was selected to maximise the likelihood of participants' ability to recall experiences and to ensure responses reflect changes in the delivery of UK cleft services since 1995 (for more information see Sandy et al, 1998).

Although the focus of the current study was the experiences of SDM by young people with CL/P, it was deemed worthwhile to collect responses from parents of children with CL/P and HCPs involved in cleft treatment. This data provided different insights and perspectives and allowed the data to be viewed comparatively. However, as research has previously looked at HCP and parents' perspectives on SDM it was decided to only collect questionnaire responses from these participants rather than rich interview data which provides more detailed in-depth responses (Dearnley, 2005).

Procedure

The study was advertised online and via social media by the Cleft Lip and Palate Association (CLAPA), a UK charity for those with CL/P. Parental/guardian consent was required for participants aged under 16 years of age. Interviews were conducted over an online messenger system or by phone. Parents of children with CL/P and HCPs were directed to the online survey. Questions were predominantly open-ended, allowing for the collection of rich, qualitative data (Emde and Fuchs, 2012).

Analysis

Responses were analysed using inductive thematic analysis as described by Braun and Clarke (2006). This particular qualitative methodology is useful in this context as it is used to identify, analyse and reporting patterns within data and is preferable to other forms as it is commonly used in healthcare research to collect pragmatic data about patients' experiences of treatment (Braun and Clarke, 2006). The data were read carefully to identify initial codes and relevant text before grouping similar topics into meaningful groups and assigning themes and sub-themes. Next the data were reviewed and collated to support each theme identified. The data from the online questionnaires were analysed using qualitative content analysis (Hsieh and Shannon, 2005) as this approach is particularly useful for coding written responses that are limited in detail and depth. As with thematic analysis, questionnaires were read to identify initial codes before grouping into key themes. Due to limited numbers of participants data were not quantified. The data from the content analysis were integrated with the data from the thematic analysis. The data were analysed by two researchers in increase the validity of the analysis. The analysis was then sent to participants for member checking.

Results

The integrated data from the thematic and content analyses identified five key themes: 1) Age-linked involvement in decision-making, 2) having a voice in treatment decisions, 3) parents and peers role in decision-making, 4) HCP role in decision-making and 5) satisfaction with speech and appearance.

Theme 1: Age-linked involvement in decision-making "*I've had more and more involvement as I got older*"

Throughout the interviews, the theme of age influencing an adolescent's role in decision-making occurred. Participants discussed the level of involvement they had in their cleft treatment decisions increasing with age, which was viewed by some as a natural progression.

> *"Yes I feel when I was younger it was more of an adults decision (especially as a baby) but we get more freedom to choose as we get older." (Young person (YP) 9 aged 25 years).*
>
> *"I've had more and more involvement as I got older as when I was younger I didn't really understand what was going on I don't think." (YP 10 aged 16 years).*
>
> *"as soon as I turned 18 I requested that things came through me um, and then I made the decisions about whether I wanted further operations or not from then... before 18 I didn't feel very involved at all really" (YP4; 19 years).*
>
> *"the operations and treatment I've had were necessary and I had them when I was young. But around 16 I got the overall decision." (YP 5, aged 17 years).*
>
> *"He will now make the final decision in any treatment. He is "old enough now [aged 15 years] that [his parents] can only advise."* (P1)
>
> *"He has always had the main role, especially at his age [12 years of age]."* (P2).

Despite this "natural progression", there was a discrepancy in the ages at which parents, HCPs and young people viewed adolescents' maturity and competence as suitable for the decision-making process, and therefore when they should be given full decision-making capacity. This age was reported to be as young as seven years

old (*"…about seven")* up to eighteen years old ("…*as soon as I turned 18 I requested that things came through me*").

The parents seemed more likely than the young people to assume their child was "*too young*" to become involved, and this would increase along with their age. Respondents to the HCP survey indicated difficulties and inconsistencies with decision-making involvement. For example, it was highlighted that material was not always presented in an age appropriate format, or schedules for treatment were too short to allow children to consider treatment options fully. One respondent to the HCP survey explained children under the age of 10 years have little involvement, while another stated that they assess whether a child has "*sufficient maturity and understanding to be involved in the decision-making process*."

Overall HCPs and adolescents generally agreed that having some involvement that gradually increased over time. Although the age range varied, most participants who gave an age suggested from 8-10 years onwards should be the point of increased involvement in decision-making.

> *"I didn't really have the choice…when I was 11…it was My Mum [who made the decisions] up until when I was asked about further aesthetic surgery when I was 12/13. It seemed to be all my choice from then on."* (YP9 aged 25 years).
>
> *"I feel when I was younger it was more of an adult's decision (especially as a baby) but we get more freedom to choose as we get older…from about seven."* (YP6 aged 17 years).
>
> *"I was old enough at 15 to start understanding what would be happening."* (YP2, aged 20 years).
>
> "*She [12 years old] does what the Doctors feel is needed."* (Parent (P)5)
>
> *"He will now make the final decision in any treatment. He is "old enough now [aged 15 years] that [his parents] can only advise."* (P1)
>
> **"***My son understood enough at 10 years old to take on a major role in his own treatment."* (P8)
>
> **"***My son [aged 8 years] is too young to understand why he's having these operations."* (P9).

> *"Some parents do tend to assume their children aren't as capable as they actually are to make decisions. We take the view they should be involved from 8-10 years old but sometimes parents will dominate consultations until 15-16 years of age."* (HCP4)

Theme 2: Having a voice in treatment decisions *"I didn't get to voice my opinions."*

Adolescents' felt that it was important to have some involvement in the decision-making process. The importance of having the option to express thoughts and opinions during treatment discussions was stated throughout the interviews; this was also echoed in the parent surveys. This should include giving young people the space to give their opinions and concerns about treatment. The theme of "having a voice" was linked to a sub-theme of feeling pressured into treatments.

> *"Those involved do need to be able to be involved enough to say whether or not they want an operation and I think that the only way to be involved is by choosing the way things are done not just that they are done." (YP6, aged 17 years).*
>
> *"as they develop into young adults I think (it's) more important than ever to ensure they feel in control of their path, not to (be) force(d) into anything they are not happy with." (P6).*
>
> *"He is old enough now that we can only be advised. He has to make the final decision."* (P1).
>
> *"He has always had the main role… he gets to decide his own cleft journey."* (P2).
>
> *"At one appointment, despite being 14 the surgeon directed all the questions to me and made it clear that it was my decision, even if my dad had the legal right."* (YP9 aged 25 years).

The significance of making the final decision regarding cleft treatments was emphasised, along with their right to be involved in the process. One participant stated that although HCPs made the majority of the decisions surrounding her cleft treatment, she had the "*overall decision…to choose whether [she does] or not.*" Another participant took control of her decision-making at the age of 18 but previously did not "*feel very involved at all*" which she "*didn't particularly like*." Two parents of children aged eight and 12 stated their children had no role in the

decision-making process and identified their own involvement, with specialists as the most significant. This view was supported by one HCP who said that sometimes "parents struggle to let go" and that this is where they as professionals had to "steer the process to ensure they have a say". A respondent to the HCP survey recognised that children's voices have "the tendency to be lost in healthcare", whilst "multidisciplinary team meetings" (MDTs) can be "overwhelming". However, the respondent also acknowledged that psychology services were able to support children in being heard.

> *"Yes, so they [HCPs] can give me some medical advice but ultimately the decision is mine." (YP6, aged 17 years).*
>
> *"I make the final decision and my parents help me to decide but the overall decision is made by me." (YP10, aged 17 years).*
>
> *" I think they should be always be the centre of decision making. As babies they have no choice to be dragged from hospital appointment to hospital appointment and surgery is compulsory but as they develop into young adults I think it more important than ever to ensure they feel in control of their path, not to made force into anything they are not happy with. I think this way they would be more happy to make decision all through life about their cleft journey treatments."* (P2).
>
> *"Those involved do need…to say whether or not they want an operation and I think that the only way to be involved is by choosing the way things are done not just that they are done."* (YP6, aged 17 years).
>
> *"Yes, I would like to have had more of a say in how often I have reviews – maybe once every year."* (YP 8, aged 17 years).

Sub-theme: Feeling pressured into treatments: Adolescents also reported that having no involvement in decision-making could cause them to feel unhappy and "forced" into treatment. This occurs because they "have to have things done… rather than want to". Especially earlier in the adolescent's treatment, parents and specialists had the main role in the process:

> "*My parents definitely had, a view that um, they would try and do any operations they could… so there were times when I didn't particularly want to have them… but my parents said it would be better in the longer term so I would end up having them.*" (YP4, aged 19 years).

> *"Unhappy, probably upset that I didn't get to voice my opinions."* (YP6, aged 17 years).
>
> "*as they develop into young adults I think [it's] more important than ever to ensure they feel in control of their path, not to [be] force[d] into anything they are not happy with*." (HCP2).
>
> *"[it's] still important for everyone [to have a voice]."* (YP5 aged 17 years).
>
> *"My wife and I try really hard to provide advice but not to influence her decision as it is important that it's her choice"* (P10).
>
> *"Sometimes parents cannot see that they are pressurizing their children into operations due to their own fears"* (HCP4).
>
> *"I have seen professionals push children too hard in consultations, particularly when it comes to surgeries, because they feel strongly that the child should have the procedure"* (HCP3).

This suggests an importance in ensuring adolescents are given a voice in decisions about their cleft treatment, especially since all of the adolescents in this research stated a preference for an increased or similar level of involvement in their cleft treatment decisions.

Theme 3: Role of parents and peers in decision-making "*My mother is the biggest supporter"*

Young people identified the importance of both their relationships with parents and their peers in making decisions surrounding cleft treatments. They identified that parents wanted what was best for their child, but highlighted that at times they felt under pressure to undertake treatments their parents had chosen for them. They also highlighted pressure from peers especially regarding aesthetic surgeries.

> *"With help from family, and friends! But also society has definitely helped impact my decision making!"* (YP2, aged 20 years).
>
> *"I try to give my son the support he needs to make informed decisions."* (P8).
>
> *"My parents would offer their opinions on any treatments, as they are more likely to pick up on any changes, but I would not allow them to have the final say*." (YP9, aged 25 years)

Sub-theme: Support from parents and family members: The theme of support from parents and peers ran throughout the data. The majority of participants discussed support they had received from their parents and other family members, both in a practical and emotional capacity. Participants understood that family members were available for guidance and support should they require it.

> *"My parents are very helpful and conscious of my opinions and thoughts […]" (YP3, aged 15 years)).*
>
> *"[…] My mother is the biggest supporter […]. My mother would always go to appointments with me and help us and the HCPs discuss treatments together". (YP7).*
>
> *"As hard as it is to send your child down for operations, the end result is amazing. The most important thing is that they feel in control of their own destiny."* (P7).

These findings demonstrate parents' awareness of providing support and protection for their child as well as a space for their own self-expression.

Sub-theme: Parents want what is best: There was an underlying sub-theme amongst the adolescent and parent data suggesting that parents want to do what is best for their child. Two participants expressed this belief in an assured manner, suggesting security and confidence in their support networks.

> *"[…] and my mum gives advice as well because she has always been there for me and obviously wants the best for me." (YP7, aged 18 years).*
>
> *"[Parents] would always want what is best for me […]" (YP2 aged 20 years).*
>
> *"My parents still provide opinions…"* (YP4, aged 19 years)
>
> *"My wife and I try really hard to provide advice but not to influence her decision as it is important that it's her choice"* (P10).
>
> *"Parents mostly want what is best for their children and sometimes that is learning to take a step back and let them develop their own autonomy."* (HCP3).

This demonstrates the value of children with CL/P feeling supported and advocated when pursuing treatments. However, one adolescent participant expressed doubt in

their parents' abilities, in comparison to HCPs, to recognise what is best for the child regarding cleft treatments.

> *"I would like to share the decision more with HCPs rather than my parents as the HCPs know what they are talking about and know what's best for you but parents are not always the best ones to help you. […]." (YP9, aged 16).*

> *"Okay, since I'm getting older, I would like to be go into the consulting room by myself instead of having my parents with me as I feel that when my parents are in the room with me, I don't express and voice my concerns as I wanted to. When I have my next cleft palate review, I will just go in by myself without my parents accompanying me if the cleft surgeon lets me… I just don't want them to get upset if I voice my real concerns such as having a little friendship group, getting negative comments about the way I speak which makes me feel depressed- feel more confident on my own and will be able to say what I am feeling more confidently."* (YP 8, aged 17 years).

> *"We try to tune in to the situation, the subtle cues that the child is struggling with something they aren't sharing with the parent, or if the child seems ok about something, but the parent is the one who sounds distressed. This allows us to try and support the child to have more involvement"* (HCP3).

These findings suggest that children with CL/P may view their parents and family members as a source of emotional support whereas HCPs may be viewed as more appropriate for practical support due to their expertise and knowledge surrounding CL/P.

Sub-theme: Pressure from parents: Some adolescents reported feeling pressured into treatments by their parents. One participant reported that she felt she was "forced" into treatments by her parents and another took control of her decision-making at the age of 18 but previously did not "*feel very involved at all*" which she "*didn't particularly like:*"

> "*but my parents definitely had, a view that um, they would try and do any operations they could aesthetically wise, just to improve anything so there were times when I didn't particularly want to have them… but my parents said it would be better in the longer term so I would end up having them.*" (YP4, aged 19 years).

> *"Sometimes parents cannot see that they are pressurizing their children into operations due to their own fears"* (HCP4).

Sub-theme: Peers as positive and negative influences on decision-making:

Participants stated that their friends and peers played a role in their decision-making regarding treatments. One participant stated a desire to blend in with peers and that he did not want them to see his lip pre-operation as "*it stood out*". Another explained she felt "*a kind of peer pressure*" from her "*cleft friends*" regarding the surgeries they have had and the expected route she should take with her treatment. She reported that her "*normal friends*" apply pressure to her also, telling her she "*would look great with [aesthetic] surgeries on my nose and lip*"." For one participant, negative reactions from peers played a part in her decision-making process:

> "*When I got bullied, I would accept any operation at the time to change who I was, but if I wasn't I probably wouldn't be too bothered…I mean I would of probably still got it done, but it just helped secure my decision.*" (YP2, aged 20 years).

Others talked about positive support from peers who have provided the confidence to make their own decisions:

> *"With help from family, and friends! But also society has definitely helped impact my decision making!"* (YP2, aged 20 years).

Theme 4: Role of HCPs in the decision-making process "*you can have more trust and they get to know you*"

Young people identified that HCPs could have a positive influence on decision-making through the trust they held in their clinicians, but also negatively through exclusion in the decision-making process.

> *"My son's cleft surgeon is great. He really makes us both feel at ease."* (P7).
>
> *"I've had the same orthodontist all the way through it…he's great."* (YP3, aged 15 years).
>
> *"…my orthodontist and otolaryngologist are cool.*" (YP8, aged 17 years).
>
> *"I remember being a little unsure…to talk with my doctors about what I wanted…I guess I didn't want to seem unhappy with previous surgeries or the way things were at the time.*" (YP7, aged 18 years).

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Sub-theme: Trust in HCPs: Throughout the interviews, all participants made reference to the expertise and support HCPs can provide and some discussed the importance of familiarity and trust. Some of the participants felt comfortable in sharing their treatment decisions with HCPs.

> *"I think that both [HCPs and parents] are very helpful because professionals know what they are talking about and can give us detailed advice […]." (YP3, aged 15 years).*
>
> *"[…] I think that's one of the most important things [having a good relationship with HCPs] then you can have more trust and they get to know you and know what can help you." (YP5).*

Sub-theme: Exclusion by HCPs: Throughout the interviews, participants discussed incidences of HCPs failing to provide them with regular appointments, or the necessary information required for decision-making; in some cases feeling excluded from conversations altogether. This resulted in participants feeling unsure of what to expect, lacking opportunities to voice concerns, and missing relevant knowledge related to their condition.

> *"[…] I feel like I should have more regular multidisciplinary cleft team reviews as I'm having one next month but the last one I had was when I was 15 years old so feel that it is a long time to wait between reviews and if I have any concerns about myself […]." (YP8, aged 17 years).*
>
> *"[…] when I was younger, it used to make me feel scared that I didn't know what was going to happen to me when I was in hospital." (YP9, aged 25 years).*
>
> "*orthodontists always talk (too) quiet(ly) and in words that I never understood so it's always kinda hard.*" (YP2, aged 20 years).
>
> "*They still do even at 20! They will bring my parents in and still like aim the discussion at them… it's funny to watch but also kinda strange.*" (YP2 aged 20 years)
>
> *"I have seen professionals push children too hard in consultations, particularly when it comes to surgeries, because they feel strongly that the child should have the procedure"* (HCP3).

Theme 5: Satisfaction with speech and appearance "[I] *wanted a better smile"*

The desire for increased confidence, improved self-esteem, and improved appearance and speech emerged as a theme throughout the data as motivation for elective cleft treatment. One participant stated she "*wanted a better smile [through surgery] and have more self-esteem*"; she started speech therapy as she felt she was "*too shy at school*" and wanted to increase her confidence. The participant below discussed wanting surgery to improve their appearance and feeling empowered by their parents to make that decision:

> *"When I wanted to change the way I looked I would bring it up with my parents […] they wanted me to do what I wanted and would make me feel good." (YP8, aged 17 years).*
>
> *"On my last operation [at 10 years of age] mum didn't want me to have the operation but I did… I nagged my mum, we had a long talk, then she said "it's your decision not mine" so I said "I want it done". The operation was the best decision I ever made I can smile better."* (YP1 aged 12 years).
>
> "*Me, my parents and my orthodontist decided together for me to have braces as I wanted a better smile and have more self-esteem.*" (YP3, aged 15 years).
>
> *"I think my son's confidence was greater having surgery."* (P2).

Satisfaction with speech and/or appearance also appeared to be related to self-confidence, stigma and was influenced by other people's judgements. Participants talked about these factors in relation to SDM and how they had/would want a choice to have elective surgeries to improve them:

> *"[…] I am left with a slight lisp which I would love to try and eradicate as it really decreases my self-confidence and ability to make friends." (YP10, aged 17 years).*
>
> *"I didn't like talking about my cleft lip. I suppose I put my own stigma on it when I was younger and felt that it made me different and odd." (YP4, aged 19 years).*
>
> *"…for my nose [surgery to straighten it]…when I am 17 not 21, I have to brace fitted first then they will do the jaw [surgery]…[the] nose is for appearance and then the jaw is because I have a under bite."* (YP1, aged 12 years).

Appearance could also be a negative factor in decision-making with adolescents suggesting that at times they may choose to have surgeries based on their experiences of being bullied for looking different:

> "*Also like when I got bullied, I would accept any operation at the time to change who I was.*" (YP2, aged 20 years).
>
> "*When my daughter was about 14/15 years old she became a bit obsessed with her surgeries because she was convinced it would improve her looks and make it easier to fit in with others kids her own age.*" (P12).

Appearance and/or speech impacting upon confidence also emerged as a theme within the parent surveys. Parents linked aesthetic cleft treatments with increased confidence. Upon completion of the treatment, participants reported increased confidence and self-esteem. One participant declared his lip revision "*the best decision (he had) ever made*" and he and his parent reported feeling more confident ("*his confidence about his appearance went through the roof*").

Discussion

The findings from this study identify that young people with CL/P feel that their involvement in decision-making should gradually increase over time. Findings were mixed as to when this gradual SDM process should begin, but it was generally considered that around the age of 8-10 seemed the earliest appropriate age depending on the individual maturity of each child. On the whole young people felt involved in the treatment decisions but at points felt they were unable to challenge their parents' decisions or felt that they were not supported enough by HCPs to take an active role in SDM. Close family relationships, pressure and/or support from peers and trusted relationships with HCPs were all implicated in the level of involvement in SDM, and the type of decisions young people made. Appearance and

speech were often key reasons for seeking elective treatments and in some instances were linked with bullying. These factors should be considered by HCPs working in cleft when involving young people in SDM.

The gradual increase in inclusion in SDM outlined by participants is supported by previous research that has suggested that graded involvement minimises the risk of overwhelming children (Coyne et al., 2006; Houston and Coad, 2007). There are multiple factors that may influence a child's ability to participate in SDM, including cognitive ability, prior experience, level of insight, nature of illness, family background and education (Coyne et al., 2006). As a result, children's needs regarding SDM should be perceived as situation-specific rather than based on age alone (Alderson, 2007; Coyne & Harder, 2011).

Although not all children and adolescents want involvement in SDM (Hall et al., 2012), this should be determined on an individual basis; adolescents should be given the opportunity to voice their opinions about their treatment. Having a voice in SDM can facilitate children's development of a sense of self (Hallstrom and Ellander, 2004), can decreased anxiety and increase sense of control and value (Tieffenberg et al., 2000). Coyne et al., (2006) suggest children may want the opportunity to participate in discussions surrounding treatment so they can voice their needs, rather than having full responsibility for decision-making.

Previous studies have highlighted the importance of trust between HCPs and young people for facilitating SDM by encouraging discussion of concerns, sharing personal information and increasing willingness to ask questions (Joseph-Williams et al., 2014). This is particularly important as young people may be more likely to accept

HCPs as experts possessing special medical knowledge which may make them feel less confident in asking questions or challenging decisions (Coyne et al., 2014).

Parents were viewed by adolescents as having the best interests of their children at heart (Nelson et al., (2012). However, this should be considered alongside the findings from this and previous studies that adolescents sometimes felt pressured into having treatments recommended by their parents (Bemmels et al., 2013). HCPs should be mindful of forceful parents and aware that parental involvement within decisions may not be equal to SDM.

The study also emphasised the role that peers may have on influencing adolescents' choices regarding cleft treatments. Tiemens et al (2013) reported that friends may act as a protective buffer and support coping which may enhance self-confidence to make decisions around treatments. Literature surrounding bullying as a factor in the decision-making process suggests this may encourage adolescents to engage in appearance altering surgeries to reduce bullying (Bemmels et al., 2013).

The findings that young people are influenced by appearance and speech difficulties is supported by the literature into these difficulties in children with CL/P (Hunt et al., 2007; Rumsey and Stock, 2013). This highlights the importance of support and access to adequate intervention, and the need for ensuring that the well-being and level of satisfaction of young people with CL/P is continuously assessed and achieved. This would include a key role of psychologists along with other HCPs. This support may include access to other forms of intervention that are non-surgical, such as social skills training to enable them to cope better with the teasing and other negative social encounters they may face (Norman et al., 2014).

Access to relevant information regarding treatment is central to being able to make an informed decision (Coyne et al., 2006). Findings have suggested providing children with information regarding treatments, including the accompanying risks and benefits, aids children's understanding of the process and implications (Lewis & Lewis, 1990). A lack of information increases children's fears and anxiety surrounding treatments, causing them to feel unprepared for procedures and reduces self-esteem (Coyne et al., 2006). Consequently, excluding children with CL/P from conversations about their treatments fails to promote SDM and healthy psychological well-being. The evidence from this study suggests that some HCPs may require training in supporting SDM.

The current study used a small sample size to explore individual examples of SDM. While the number of participants were appropriate for thematic analysis and it was felt by the researchers that data saturation had been reached (the same data were coming up over each interview; Fusch & Ness, 2015), the study could have benefitted from further recruitment. This would have strengthened the findings and allowed for generalisations to be made across the UK population. Specifically, it would have been useful to ensure a sample from each UK cleft centre to compare and contrast processes across the UK. A longitudinal study may also collect rich, extensive data exploring changes in involvement in SDM over time.

Interviews were conducted via the telephone or online, with no face-to-face contact. As a result, this could be a limitation as emotional cues may be missed. However, this method of data collection was chosen by the young people in this study, with a general preference for online messenger interviews; a form of communication they feel more comfortable with allowing for more open communication. This could be particularly true for young people with appearance

and/or speech related concerns where their engagement in face-to-face interviews may be restricted (Fox et al., 2007).

The current findings suggest implications for future practice by highlighting the importance of adolescents' involvement in SDM and the need for a gradual approach to SDM in cleft care. Furthermore, it may be beneficial for adolescents to have the opportunity to express concerns in a less intimidating environment than current multidisciplinary team meetings where they may feel less able to express their views.

The current study identified that adolescents do want to be involved in decision-making surrounding cleft treatments. Participants felt they were involved in SDM, however, there were also missed opportunities to express themselves and felt information surrounding treatment options was omitted by HCPs. The current study found that although participants were generally satisfied with their level of involvement, improvements were required. Finally, the current study highlighted the importance of SDM for psychological well-being by identifying adolescents' need for autonomy and to feel supported and listened to.

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